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How Grandparents Experience the Death of a Grandchild With a Life-Limiting Condition

Michael J. Tatterton, PhD, MSc, RNC, RHV[1,2], and Catherine Walshe, PhD, RN[2]

Abstract

Traditionally, family-focused care extends to parents and siblings of children with life-limiting conditions. Only a few studies have focused on the needs of grandparents, who play an important role in the families of children with illness and with life-limiting conditions, in particular. Interpretative phenomenological analysis was used as the methodological framework for the study. Seven bereaved grandparents participated in this study. Semistructured, individual, face-to-face interviews were conducted. A number of contextual factors affected the experience of bereaved grandparents, including intergenerational bonds and perceived changes in role following the death of their grandchild. The primary motivation of grandparents stemmed from their role as a parent, not a grandparent. The breadth of pain experienced by grandparents was complicated by the multigenerational positions grandparents occupy within the family. Transition from before to after the death of a grandchild exacerbated the experience of pain. These findings about the unique footprint of grandparent grief suggest the development of family nursing practice to better understand and support grandparents during the illness of a grandchild, in addition to bereavement support.

[1]Martin House Children's Hospice, Wetherby, UK
[2]Lancaster University, UK

Corresponding Author:
Michael J. Tatterton, Consultant Nurse in Children's Palliative and End of Life Care, and Head of Nursing, Martin House Children's Hospice, Grove Road, Boston Spa, Wetherby LS23 6TX, UK.
Email: MTatterton@martinhouse.org.uk

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Family-centered care, a cornerstone of children and young people's nursing in the United Kingdom, is a multifaceted concept that has developed over the last 60 years to a point where it has become inextricable from practice. However, many services do not define "family" broadly when developing or delivering care services to children and families, focusing largely on the needs of the sick child and his or her parents. The result is that grandparents, and their role and needs, remain largely invisible (Murphy & Jones, 2014; Youngblut, Brooten, Blais, Kilgore, & Yoo, 2015). In children's palliative care, there is little research on grandparents and their role or support needs.

In the United Kingdom, there are estimated to be 50,000 children living with a life-limiting condition (32 per 10,000 population; Fraser et al., 2012). In 2012, more than 2,000 children and young people aged between 1 and 19 years died in England and Wales (National Guideline Alliance, 2016). Bereavement support is regarded as an integral part of children's palliative care. Traditionally, bereavement care following the death of a child is extended to their parents and siblings with few services offering support to extended family members. Current understanding of the emotional needs of grandparents is largely limited to the generalization of work with parents, siblings, and health workers (Gilrane-McGarry & O'Grady, 2012).

Grandparents' perception of their role within a family, and of the dynamics within the family have an impact on the experience of grandparents. Grandparents have an important function within the bereaved family (Nehari, Grebler, & Toren, 2007), depending upon the role that grandparents assume and which the family expects. A number of studies (Fry, 1997; Gilrane-McGarry & O'Grady, 2011; Moules, Laing, McCaffrey, Tapp, & Strother, 2012) have identified that much of grandparents' preoccupation was with their efforts to reduce the pain of the child's parents, rather than with their own grief. Grandparents showed an awareness of the complexity of the pain, appreciating their dual role as both a grandparent and parent. Grandparenting experiences did not focus on the sick child, but included taking a broader responsibility in meeting the needs of the family. The perception of "being needed" within a family seemed to have a positive effect on the experiences of grandparents (Fry, 1997), and grandparents with a less defined role following the death of a grandchild expressed sadness both in relation to their function and their grandchild's death.

The experience of emotional pain is frequently highlighted in the grief and bereavement literature. A specific aspect of grief, disenfranchised grief, results

from both society's perception (Nehari et al., 2007), including professionals caring for the dying child (Moules, McCaffrey, Laing, Tapp, & Strother, 2012), and grandparents themselves, where individuals endeavor to protect their children and surviving grandchild by suppressing their own grief and pain (Gilrane-McGarry & O'Grady, 2011).

Bearing witness to a grandchild's illness and death and their desire to protect their children and an inability to do so is a recurrent cause of emotional pain in grandparents. The act of watching and sense of helplessness due to being unable to remove pain from their child caused immense emotional pain (Gilrane-McGarry & O'Grady, 2012), the full extent of which was often not disclosed to parents in an effort to protect them, further exacerbating their disenfranchisement (Moules, McCaffrey, et al., 2012).

Cumulative pain has been highlighted to varying degrees, including the suggestion of double or triple pain (Moules, Laing, et al., 2012). Cumulative pain is more than simply grieving for multiple generations, as other cumulative factors influence grandparents' experiences. These include subsequent changes in their son or daughter (Gilrane-McGarry & O'Grady, 2011); survivor guilt (Fry, 1997); helplessness, feelings of social isolation, and change in role (Nehari et al., 2007), all of these experiences creating a sense of overwhelming insurmountable pain and emotional disorientation in grandparents (Gilrane-McGarry & O'Grady, 2012).

Limited research to date has focused on the experiences of grandparents of children with life-limiting conditions. In addition to this empirical study, a meta-ethnography was published that demonstrates how the influence of family, their relationship with their deceased grandchild, and the multigenerational perspectives of grandparents affect their grief experiences (Tatterton & Walshe, in press). This empirical study explores the broader contextual implications of childhood life-limiting conditions for grandparents, including the complex health needs and degenerative disease trajectories of their grandchildren (Noyes et al., 2013).

Aim

The aim of this study was to explore how the context of family affects the experience of grandparents and how grandparents conceptualize the illness and subsequent death of their grandchild.

Method

Interpretative phenomenological analysis (Smith, Flowers, & Larkin, 2009) was used as the methodological framework to explore bereaved grandparents'

experiences of the death of a grandchild from a life-limiting condition by seeking a richer understanding of how they define their experiences. The consolidated criteria for reporting qualitative research (COREQ) guidelines (Tong, Sainsbury, & Craig, 2007) were used.

Recruitment

Participants were recruited through children's hospices in the North of England. Information packs were distributed by the hospices to bereaved parents of children that were known to their services. Contact details for grandparents were not held by the hospices. A covering letter explained the study and asked parents to pass the information pack onto grandparents. The pack contained a participant information sheet, expression of interest form, and a prepaid envelope. Grandparents were asked to return the expression of interest to indicate their willingness to participate, or to request further information. Grandparents were then telephoned using the details provided to arrange an interview. Participants eligible for inclusion in the research met the following criteria:

- identified themselves as fulfilling a grandparenting role;
- had a grandchild who died in the previous 6 to 24 months;
- had a grandchild who died following a life-limiting or life-threatening condition (ACT/RCPCH, 1997);
- were able to speak English.
- Grandparents who were the principal carers for a child were not included, as this study focused on those in a secondary caring role.

Ethical Considerations

Ethical approval was sought from, and granted by, Lancaster University Research Ethics Committee (FHMREC13012). National Health Service (NHS) ethical approval was sought, but not required due to the secondary caring role of the grandparents included in the study. Participants were informed that participation was entirely voluntary; participants were not incentivized to partake in the research. Consent was sought at the time of interview. The participants' right to withdraw was made clear; all were asked to sign a consent form. To protect confidentiality, participants, and people they named, were given gender-appropriate pseudonyms. A distress protocol was in place to manage any disproportionate emotional discomfort expressed or experienced by participants during their interview, based on the work by Draucker, Martsolf, and Poole (2009).

Table 1. Interview Guide.

Can you tell me about your experience of being a grandparent to [child's name]?
Depending on the disclosures made when answering the initial question, clarification was sought around a number of topic areas, including:
• Their previous relationship with their grandchild;
• Expectations and relationships with the child's parents before and after the death;
• Expectations and relationships with the child's siblings before and after the death;
• Their feelings;
• Advice they would offer to others;
• Their identity as a grandparent, particularly if the deceased child was their only grandchild.
Other experiences of childhood deaths, and their impact;
Experiences of other losses or serious illnesses, and their impact.

Data Collection

Semistructured interviews were conducted in the homes of the participants, audio-recorded, and transcribed by the researcher (M.T.); the interview guide is presented in Table 1. Field notes were made immediately following the interview. Transcripts were cross-checked against the audio recording a second time, before being formatted for interpretative phenomenological analysis.

Data Analysis

Data were analyzed using interpretative phenomenological analysis (IPA) primarily by M.T., and discussed with C.W. and S.M. as academic supervisors. Qualitative thematic analysis was undertaken, enabling the development of rich idiographic descriptions, contextualized in the lived experiences of individual participants. Coding was generated directly from the verbatim interview transcripts. A priori codes were not used. NVivo (Version 10.2.2) was used to manage the coding and analysis.

Rigor was assured through keeping a self-reflective journal throughout the research process, and active engagement in discussions and critical thinking with academic supervisors and online IPA forums. Brocki and Wearden (2006) discuss how an IPA approach encourages researchers to go further than other qualitative approaches in addressing issues surrounding reflexivity, which explicitly recognizes the interpretative facet of IPA in its theoretical grounding (Newton, Rothlingova, Gutteridge, LeMarchand, & Raphael, 2012; Smith et al., 2009). Academic supervisors of the primary author read sections of analyzed transcripts, which were then discussed and challenged during supervision. The initial literature review completed prior to the empirical research helped to

Table 2. Summary Demographics of Participants.

Assigned pseudonym	Family role of grandparent	Age of grandchild at death (years)	Life-limiting illness of grandchild	Time since death
Olive	Maternal grandmother	3	Cancer	10 months
Robert	Maternal grandfather			
Christine	Maternal grandmother	10	Neurodegenerative, genetic	9 months
Gary	Maternal stepgrandfather			
Jenny	Paternal grandmother	3	Cancer	12 months
John	Paternal grandfather			
Anne	Maternal grandmother	2	Neurodegenerative, genetic	23 months

ground the researcher in existing research, reducing personal bias, and ensuring access to multiple, evidence-based perspectives of grandparental grief, rather than relying on only those of the researcher gained through clinical practice.

Findings

The interviews took place between February and September 2014. The mean interview length was 1:14 hr (range 0:32-1:43 hr). A total of seven grandparents participated in the study. A summary of the grandparent and grandchild demographics are detailed in Table 2. The findings have been structured thematically; a total of 17 themes were identified from the transcripts, which were arranged into four groups of superordinate themes, namely, the experience of emotional pain; the conflicting roles of parent and grandparent; transition from before to after the death of a grandchild; and sources of motivation, drive, and resilience (illustrated in Table 3).

Emotional Pain Experienced by Grandparents

The experience of emotional pain was the most frequently cited experience. It was rarely discussed in isolation, illustrating the cumulative effect of painful experiences. Grandparents' experiences were peppered with emotionally painful experiences, starting with the diagnosis or recognition of the life-limiting condition of their grandchild and continuing throughout the child's illness, death, and into bereavement:

> It was the treatment year, it was the new baby coming, losing Hannah, the stress that I saw [my daughter] go under, the grieving from both, the pressure that it put on them two. So for three years I have been so strong. (Olive)

Table 3. Identified Themes Relating to Grandparental Experience.

Superordinate theme	Subordinate theme
"A hurt you can't undo": The experience of emotional pain in bereaved grandparents	Cumulative pain
	Bearing witness
	Survivor guilt
	Family tension
	Disenfranchisement
"The other hat": Satisfying the demands of conflicting roles of both grandparent and parent	Parental role
	Boundaries between parenting and grandparenting
	The total support of grandparenting
	Validation
"Where do I fit now?": Transition from before to after the death of a grandchild	Helplessness
	Changes within the family
	Identity
	Enduring features of grandparenting experience
"It's a love that gets you going": Sources of motivation, drive, and resilience in bereaved grandparents	Sense of duty
	Responsibility for the family
	Continuum of hope
	Love

Grandparents described the pain caused by witnessing the child's parents' grief, but also included observations of their sick grandchild's suffering and the grief of well grandchildren:

> I felt, I suppose I felt inadequate. You want to make it right and you can't, and I think that's a driving force with any sort of mum. She wants to make it right and explain it but you can't. That was incredibly hard to see. (Christine)

The family context in which the grandparent existed had a direct impact on the experiences of the grandparent. Experiences of pain appeared to be exacerbated when there was anger or friction within the family:

> [My daughter] would get angry at the most littlest thing which I'd never seen before . . . and everything were stressful; it's been a much more stressful family erm, you know, the event of Hannah—her illness and death has brought a lot more stress to the family. (Robert)

"Family" was used by the grandparents to include their other children and their family units (usually containing other grandchildren), demonstrating the

broad perspective of grandparents within a family and explaining the phenomenon of "juggling," highlighted by participants:

> Even now that balancing is still having to be managed because people remember when people had to sort of give up their turn or you know, or I was obviously having to concentrate on one more than the other, for various reasons so it's a big issue that a lot of grandparents will try to manage. (Anne)

Grandparents reported increased pain when they perceived greater degrees of helplessness. Conversely, participants with a clearly defined role described less pain:

> You feel strong all your life, you're always there and if there's any problem for your daughter, you can usually sort it out—in my case, I've been fortunate either sort it out with money or sort it out with support, but this one I couldn't do it. This one was beyond anything really. It's that helplessness that left you a bit bereft because when your daughters saying "help me," you can't. (Robert)

Grandparents expressed a reluctance to voice thoughts that created a sense of guilt, such as that associated with living beyond their grandchild and the taboos related to thoughts surrounding suffering, quality of life, and the relief that resulted from the death of their grandchild:

> Part of you doesn't want him to fight anymore, you want him to just go to sleep and I think that's—it's something else you feel you can't voice to people because people have got this sort of you know, "you shouldn't feel like that, you would want him to live" and I—no, in all honestly I didn't want him to live. I didn't want to see him suffer. If he was out of, not in any pain, that's a different thing, but he was always in pain. Tough. (Christine)

In addition, grandparents discussed an unwillingness to share their sadness and pain with their families and peer group, reporting the need to not add to the burden of their family, or to refocus support away from the parents by acknowledging their pain within their peer group. This disenfranchisement exacerbated the experiences of pain experienced by grandparents.

Satisfying the Demands of Conflicting Roles of Both Grandparent and Parent

Grandparents predominantly discussed their role, pain, and drive from the perspective of a parent, suggesting that they regarded themselves primarily as a parent. The experience of conflict of the simultaneous, dual roles presented

as anger, jealousy, or helplessness. Grandparents highlighted their need to feel useful and their need to provide various forms of support, including practical, emotional, and financial support, the latter being cited most frequently by the male participants. When asked directly about how it felt to take a secondary care role, one grandfather explained,

> It's frustrating. [At work] I was always fairly outspoken and if I thought something wasn't right, I would say it, but I didn't say much, I have to take the backseat and not say a lot. You just have to watch these things go on. I suppose every now and then I might say something, but no, it's sad and it's frustrating—that's the only way I can really describe it. (Gary)

The concept of total support was perceived and described by all grandparents, reporting their desire and ability to provide care that was boundless. Grandparents spoke of the time involved in providing responsive care, particularly at the time of their grandchild's illness and death.

The need for validation and recognition was highlighted; those grandparents with secure intergenerational relationships required less external validation. Grandparents used the research interview to validate themselves, using the other grandparents as a benchmark: "they loved Hannah very much, but she didn't know them as like she knew me" (Olive).

Transition From Before to After the Death of a Grandchild

This theme represents the changes experienced by grandparents following the death of their grandchild, often comparing the contexts pre- and post-death. The most widely discussed phenomenon in this subset was helplessness, frequently discussed alongside bearing witness. The notion of helplessness was reported from dual perspectives, again demonstrating the twofold position taken by those in a grandparenting role, where their role as both a grandparent and parent are intricately, and sometimes conflictingly, woven into their experience. The conflicting priorities of the dual perspectives, together with the changing demands and expectations of the child's parents, exacerbated the perception of helplessness within these grandparents.

The grandchild provided a focus for the whole family. Throughout the child's illness, grandparents identified strongly within the family unit, which correlates with the well-defined roles played by grandparents. Experiences of the child's illness and deterioration were shared from a perspective from within the family, using "us," "we," and "our" indicating unity and togetherness with the child's immediate family: "We knew right from then that she would never get better and we wanted her to be at home and not in the hospice" (Jenny).

This proximal positioning continued up to and included the time of death of the grandchild, where grandparents' reports of events changed subtly, using "they" and "theirs" in place of "we" and "our," implying a perceived relocation of the grandparent to outside of the immediate family unit during bereavement, at which time grandparents reported the reforming of the child's family unit:

> When she died, it had to be them as a family, not us—they were together [pause] [crying]. Yeah, we are on the edge, it looks as that you're looking in on something to be honest. [Whispers] it's like you're looking in on something. (Robert)

The movement away from the child's immediate family was discussed explicitly describing feelings of isolation and reduced support and attributing these to the reduction or cessation of the role the grandparent had played during their grandchild's illness. Grandparents reported these experiences from the perspective of an observer, over which they had little or no control of the direction or outcome of the experience.

Finally, there were elements of the experience that endured the transition from before to following death, most notably, that of love. Grandparents discussed, at length, the love they held for their grandchild, child, and child's family; indeed, the experience of emotional pain appeared to be most prominent where emotional and affectionate bonds were stronger, particularly in parent-daughter or grandparent-grandchild intergenerational relationships.

Sources of Motivation, Drive, and Resilience in Bereaved Grandparents

Grandparents highlighted a number of emotional drivers that both motivated and sustained their involvement and engagement within the family: a strong sense of responsibility, which mostly surrounded their need to parent: "we had to just support them two to keep them, to give them strength, to take away a lot of every day pressures so they could be as best as they could" (Olive).

The need to maintain hope was a frequently cited motivating factor. The perception of hope appeared to be a continuum—grandparents did not discuss a loss of hope, but a change in what was being hoped for. This was relevant to the context of the family at any given time and progressed in correlation with the prognosis and morbidity of their grandchild: "I wasn't going to see this little girl grow up, or I was unlikely to see this little girl grow up . . ." (Robert). This extended to hopes for the child after death, which included a hope that the child was not going to be alone:

> As she got nearer the time [of death] . . . I told her things about each grandparent [who was in heaven] so she'd know stuff if she got there . . . if there is somewhere, she wasn't going frightened into the unknown. That somebody would be there, to meet her, and give her the love that we'd all given her. (Olive)

The subject of the grandparents' hope oscillated frequently between their grandchild and child. Where hope related to the grandparent themselves, it surrounded a hope that they had been perceived as being useful and fulfilling the expectations of the grandchild's parents: "I hope we're of some assistance" (John).

Finally, love was discussed throughout the interviews; the implications and effects of love are woven throughout the themes explored. Overwhelmingly, it appeared that grandparents were motivated by love. They discussed the love of their child most prominently, followed by their love of their family as a collective, and their grandchildren:

> before Hannah were ill I just, I you know, I doted on her . . . I obviously loved every— snatched time I had with her. (Robert)

Grandparents who were either new grandparents, or those with fewer grandchildren, discussed the love of being a grandparent, highlighting the status and lifestyle of grandparenting, and the special relationship between a grandparent and their grandchildren:

> I'd just had my 60th birthday when Hannah was born—God, it was the best birthday present, and all my friends have all these grandchildren—all my friends who were grandparents shared the thrill of us finally being grandparents [laughs] you know. (Olive)

Discussion

Grief is the multifaceted human response to separation (attachment) and loss (grief), (Stroebe & Archer, 2013). Modern understanding of these is based on empirical studies surrounding attachment theory (Bowlby, Ainsworth, Boston, & Rosenbluth, 1956) and the study of grief (Parkes, 1981; Stroebe & Schut, 1999; Stroebe & Stroebe, 1991). In summary, the experience of the grandparents who participated in this research can be conceptualized into four key themes. Emotional pain was the most frequently discussed experience, often in conjunction with a perception of helplessness and witnessing the grief of their children. Role and experiences were expressed from a parental perspective. A number of phenomena endured the pre- and post-death bereavement

experience of participants, namely, love and helplessness, where grandparents discussed their distress at being unable to make their family "better." Several features appeared to drive grandparents, including love, responsibility of being perceived as the family elder, and the protection and maintenance of hope. Hope was reported as a continuum as what was hoped for changed, reflecting the deterioration and death of their grandchild and the experience of their child's family.

Grandparents are not the only members of a family to grieve, and, as such, there are similarities in the grief experience of grandparents and parents (Alam, Barrera, D'Agostino, Nicholas, & Schneiderman, 2012; Arnold & Gemma, 2008; Davies, Baird, & Gudmundsdottir, 2013; Forrester, 2008) and siblings (Foster et al., 2011; Jenkins & Merry, 2005; Packman, Horsley, Davies, & Kramer, 2006) of children with life-limiting conditions. The experiences of grandparents within this study have some similarities to those of grandparents who have experienced perinatal deaths (Schmid, 2001; O'Leary, Warland, & Parker, 2011; Roose & Blanford, 2011), and those who have experienced losses other than death, including incarceration (Grinstead, Leder, Jensen, & Bond, 2003), family breakdown (Doyle, O'Dywer, & Timonen, 2010), or emigration (Coall & Hertwig, 2010), where grandparents express feelings of isolation, disenfranchisement, and a lack of recognition or appreciation of their experience of loss.

Grief was a continual and evolving element of the stories shared by grandparents who participated in this study. The individual elements of grief experienced by grandparents are not unique to grandparents, nor are they individually novel or remarkable. Grandparents are not the only grievers to experience disenfranchisement, duality of roles, changing identity, bearing witness, survivor guilt—these elements are reported widely in a broad range of fields. What is significant is that grandparents reported experiencing all of these elements at once, creating a footprint of grandparental grief that is different from other grievers. What sets grandparental grief apart from the experiences of other family members is not only their grief footprint, but the breadth of the emotional pain experienced by grandparents, and the lack of control they have over their position within the family, which has a direct impact on their experience.

Grief and Identity: A Parents' or Grandparents' Grief?

Although the dual role of grandparents is highlighted in existing literature (Gilrane-McGarry & O'Grady, 2012; Reitzes & Mutran, 2004), this study provides novel insight into the oscillation experienced by grandparents between the parenting and grandparenting role. The findings of this study

suggest that for grandparents, grief is complicated by their duality of roles within a family—simultaneously acting as parent and grandparent, each with the potential to affect the other. The predominant identity assumed by participants in this study was that of a parent. This appeared to originate internally, but was reinforced by the family, particularly the child's parents, who looked to the grandparent for emotional and practical support.

The Breadth of Emotional Pain: Compounded Grief

Emotional pain is well documented in current literature, however, this study notes the breadth of pain, both in terms of longevity and sources. Current literature describes the concept of "double grief" in grandparents (Drew & Goodenough, 2006; Moules, Laing, et al., 2012), or "triple grief" (Ponzetti, 1992). This study supports these findings, and builds on them, providing further insights into the loss of a grandchild. This study found that several interrelated factors from the experience contributed to the perception of emotional pain—these extended beyond what was felt or observed by the grandparents to include the direct effects of the family. Grandparents in this study were unable to separate one event or source of grief from another, which resulted in the compounding of their feelings of grief. The findings of this study suggest that the feelings of grief are not restricted to the deceased grandchild's immediate family, but extend to include the families of the grandparents' other children and, therefore, grandchildren. The complexities associated with managing their family as a whole, including involvement with other sets of grandchildren, compounded the experience of grandparents.

Implications for Clinical Practice and Research

The findings of this study suggest that to meet the needs of grandparents, their dual, simultaneous roles of being both a parent and grandparent must be acknowledged. In addition, emotional support during their grandchild's illness should be provided to grandparents, which focuses on the definition and negotiation of their concurrent roles. Framing grandparental input as a resource would help to focus on the contributions made by grandparents, recognizing and valuing the impact of their involvement, and focusing on preserving and supporting the role.

The benefits of professionals who demonstrate family-focused care through relationship building and through working with whole families are well documented (Butler, Copnell, & Hall, 2018; Davies et al., 2013). Numerous guidelines are available to support nurses and other healthcare professionals to inform, develop, and enhance family-focused approaches to

care, including publications by the International Family Nursing Association (IFNA; 2015, 2017), and the Royal College of Nursing (RCN; 2018), focusing specifically on children's palliative care.

Many of the children who require palliative care have undiagnosed degenerative conditions (Popejoy, Pollock, Almack, Manning, & Johnston, 2017). Future research may include the experience of grandparents whose grandchildren did not have a diagnosis and the effect of culture and religious beliefs on bereavement experiences. Research could also consider the gender of the parent that links their child to the grandparents, the gender of the grandparents, and whether or not experience is affected by being a single or pair of grandparents. Finally, research surrounding the usefulness of family assessment and intervention for this population of families is also needed.

Strengths and Limitations

This study has provided novel insight into the experience of bereaved grandparents, which have theoretical transferability to policy and practice surrounding contemporary family-focused children's palliative care, however, there are a number of limitations in this research report that should be considered.

The small sample group, consistent with IPA methodology, means that only modest claims can be made based on the findings. Within IPA, and the qualitative paradigm in general, there is more of a focus on the possible transferability of findings from group to group rather than generalization. The approach to sampling meant that only grandparents of children who used children's hospice services were invited to participate. The most recent figures suggest that only 20.2% of children with palliative care need are supported by hospices (Devanney, Bradley, & Together for Short Lives, 2012). Families without the support of hospices often have less access to the ongoing, holistic support that such services offer, perhaps having an impact on the context of the family unit as a whole.

Conclusion

The grandparents in this study experienced fluctuation of identity between parent and grandparent, with a primary drive of parenting. Grandparents of grandchildren with life-limiting conditions experience multiple, progressive losses associated with the deterioration and death of the grandchild. These losses, when combined with the effects they have on the whole family and the resulting experiences of bearing witness, survivor guilt, and disenfranchisement create a footprint of grief that is unique to grandparents. These new

perspectives into grandparental experience can help to improve the care and support available to better meet their needs as a parent, grandparent, and individual who has experienced the child death.

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ORCID iDs

Michael J. Tatterton https://orcid.org/0000-0002-7933-5182
Catherine Walshe https://orcid.org/0000-0002-4531-8608

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Author Biographies

Michael J. Tatterton, PhD, MSC, RNC, RHV, is an experienced registered children's nurse and health visitor (public health nurse), working as a Nurse Consultant in Children's Palliative and End of Life Care/Head of Nursing in a regional children's hospice in the North of England, United Kingdom. His clinical and research interests focus on family-centered children's palliative care, grief, loss and bereavement, workforce development, and the safe and effective use of medicines. Recent publications include "Understanding the Bereavement Experience of Grandparents Following the Death of a Grandchild From a Life Limiting Condition: A Meta-Ethnography" in *Journal of Advanced Nursing* (in press, with C. Walshe), "Anticipatory Prescribing and Advance Care Planning in Palliative Care for Children and Young People" in *Nurse Prescribing* (2018), and "Independent Non-Medical Prescribing in Children's Hospices in the UK: A Practice Snapshot" in *International Journal of Palliative Nursing* (2017).

Catherine Walshe, PhD, RN, is professor of Palliative Care in the International Observatory on End of Life Care, Lancaster University, United Kingdom. A nurse by background, her research interests are in the field of palliative care, with a particular focus on the organization of palliative care services and the experiences of people toward the end of life. She is the editor-in-chief of *Palliative Medicine*, and on the board of the European Association of Palliative Care. Recent publications include "'Being With' or 'Doing for'? How the Role of an End-of-Life Volunteer Befriender can Impact Patient Wellbeing: Interviews from a Multiple Qualitative Case Study (ELSA)" in *Supportive Care in Cancer* (2018, with S. Dodd et al.), "A Revised Model for Coping With Advanced Cancer. Mapping Concepts From a Longitudinal Qualitative Study of Patients and Carers Coping With Advanced Cancer onto Folkman and Greer's Theoretical Model of Appraisal and Coping" in *Psycho-Oncology* (2018, with D. Roberts et al.), and "Quality of Life Trends in People With and Without Cancer Referred to Volunteer Provided Palliative Care Services (ELSA): A Longitudinal Study" in *Journal of Pain and Symptom Management* (2018, with N. Preston, S. Payne, S. Dodd, & G. Perez Algorta).